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Developing a Person Centered Fear and Dementia (FaDe) assessment tool for individuals living with a dementia

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Developing a Person Centered Fear and Dementia (FaDe) assessment tool for individuals living with a dementia

Abstract

Oral presentation at the PCE 2016: 12th World Association for Person Centered & Experiential Psychotherapy & Counseling conference, 20-24 July, New York City, USA.

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Dementia and Fear: Developing a person centred tool for practice

Uniting



Take on a
Global
Challenge



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Who we are?



Susan Stephen



Emma Barkus



Victoria Traynor



Siyu Qian



Ping Yu



Nicole Carrigan



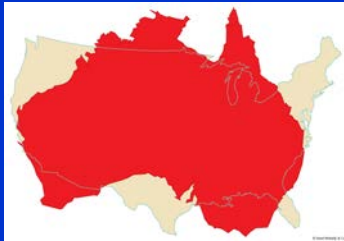
Mengxiang Li

Counselling,
Information Technology,
Nursing and
Psychology

Academics and
Practitioners



Helen Pavlik



FADe



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Aged and Dementia Health Education and Research (ADHERe)

Positive Decisions 

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Knowing the evidence

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Content Pages

The focus of this resource is improving aged and dementia healthcare services using qualitative research and practice development techniques across care settings with multi-disciplinary teams.

Our resources are as follows:



What do we know about dementia?

- ❖ Individuals living with a dementia face challenges everyday caused by difficulties with their memory and cognitive capacities
- ❖ Individuals living with a dementia benefit from positive support of their family, friends and healthcare practitioners to live a life as full as possible
- ❖ Nursing home care is not an inevitable part of dementia but most older people living in a nursing home



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RETHINKING AGEING

DEMENTIA RECONSIDERED

the person comes first



TOM KITWOOD

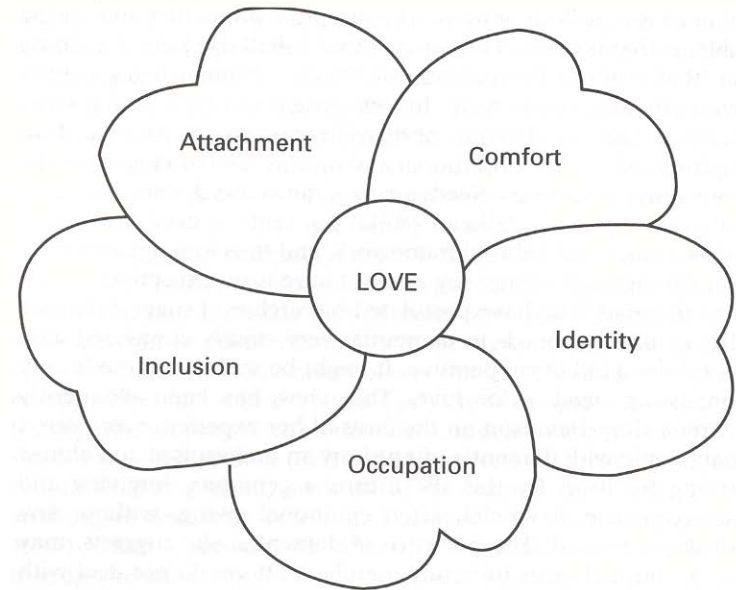


Figure 5.2 The main psychological needs of people with dementia



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Ontologies of dementia

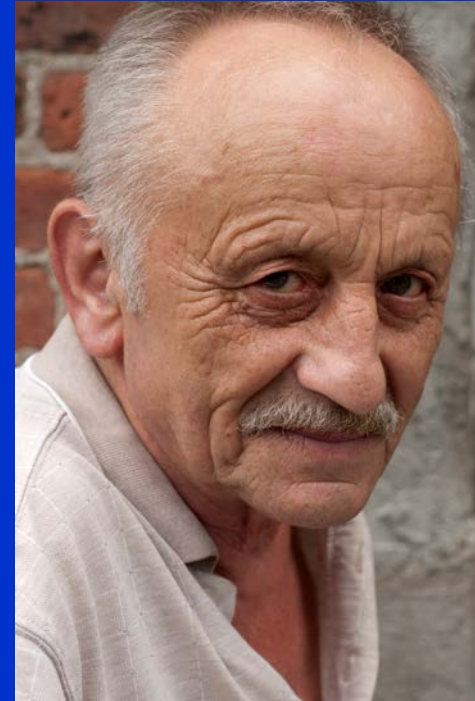
- ❖ Person centred dementia care focuses on the role of 'malignant social psychology' and the impact of carers on the individual (Kitwood, 1987)
- ❖ Medical model of 'behavioural and psychological symptoms of dementia' (BPSD) over-symptomizing the experience of living with a dementia



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What do we know about dementia and fear and anxiety?

- ❖ Current focus in clinical practice and research within dementia care is on assessing and 'managing' BPSDs e.g. Nursing Psychiatric Inventory and the Cohen-Mansfield Agitation Inventory and a range of therapies to reduce symptoms
- ❖ Lack of focus in clinical practice and research on the interaction between the environment and the individual (physical and care practices) e.g. decreasing fear and anxiety
- ❖ Our literature review found a gap in current research on fear and anxiety in



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Research Design: Generating content for the Fear and Anxiety in Dementia (FADe) tool

- ❖ Aim of the research is to develop a person centred observational tool which enables the user of the tool to identify fear and anxiety experienced by individuals living with a dementia
- ❖ Practitioners part of research team to ensure FADe has face validity and it is **simple** to use in clinical practice
- ❖ Combining qualitative and quantitative methods
- ❖ Inter-disciplinary approach generating the views and perceptions from practitioners and researchers with a range of experiences



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Research Design: Generating content for the draft versions of the FADe tool*



Stage 1: Literature review of concepts: Draft 1



Stage 2: Workshop with practitioners and service managers (n=22): Draft 2 (151 items created)

Ongoing **Stage 3:** Q Sort activity with researchers and senior clinicians (n=32 to date and aim for 50): Draft 3 (101 items reviewed)

2016 **Stage 4:** Delphi survey: Draft 4

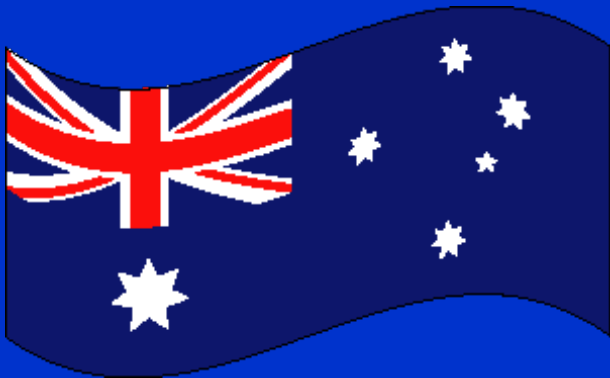
2017 **Stage 5:** Reliability and validity testing using observational methods: Final version



Q Sort: Demographic profile of participants



13%



87%

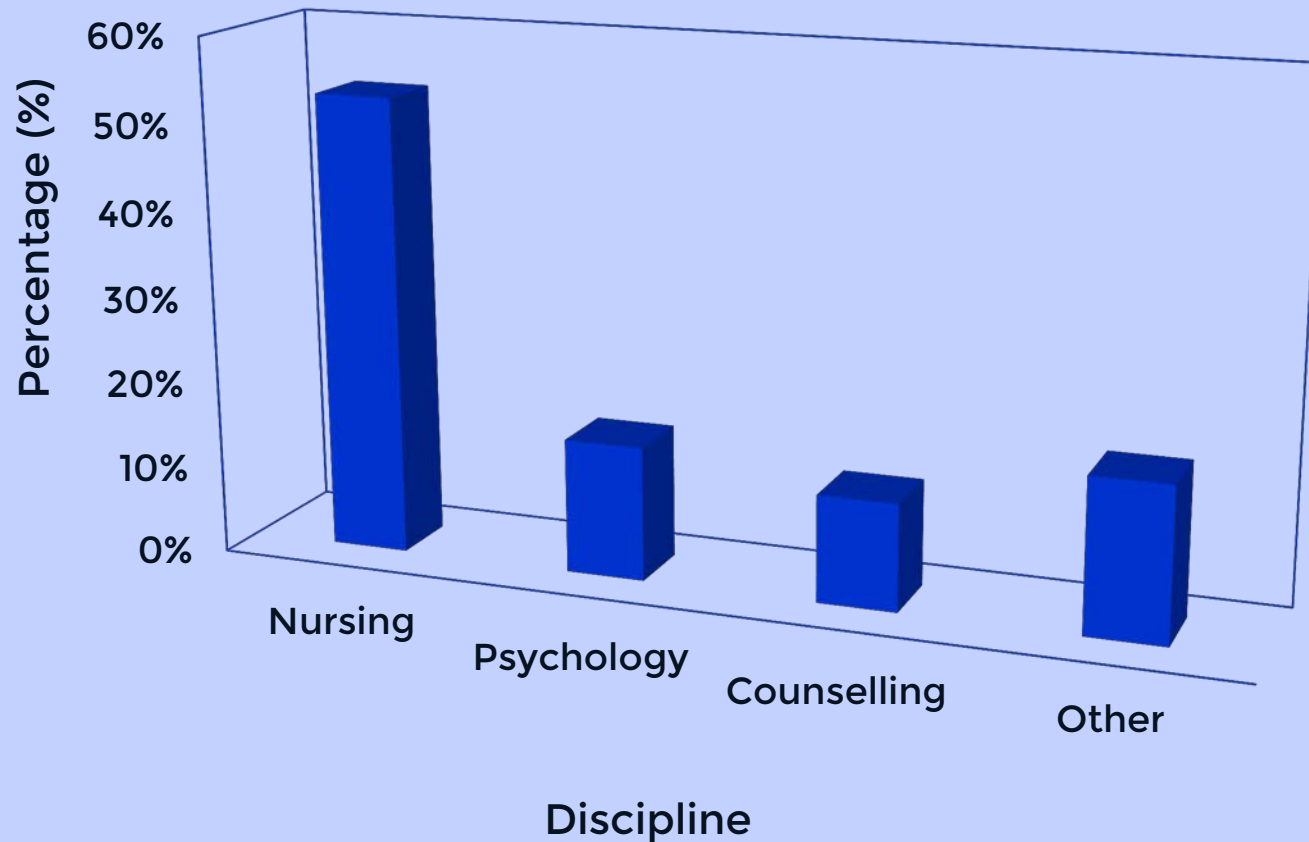


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Q Sort: Demographic profile of participants cont'd

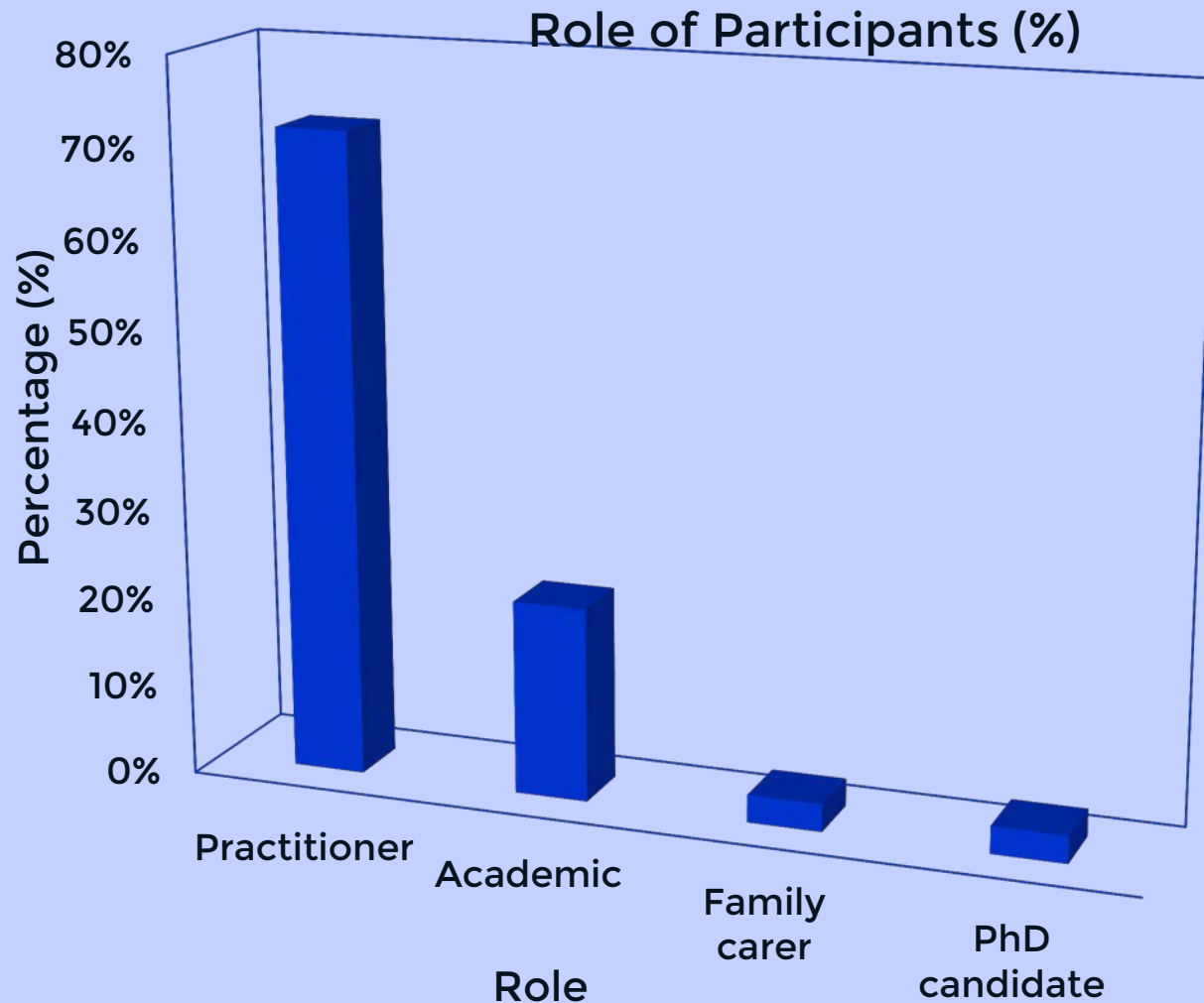
Discipline of Participants (%)



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Q Sort: Demographic profile of participants cont'd



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Q Sort: Categories created by participants

- ❖ Number of categories (groups of cards)

- Mean 11.3 ± 4.3

- Range: 3-21



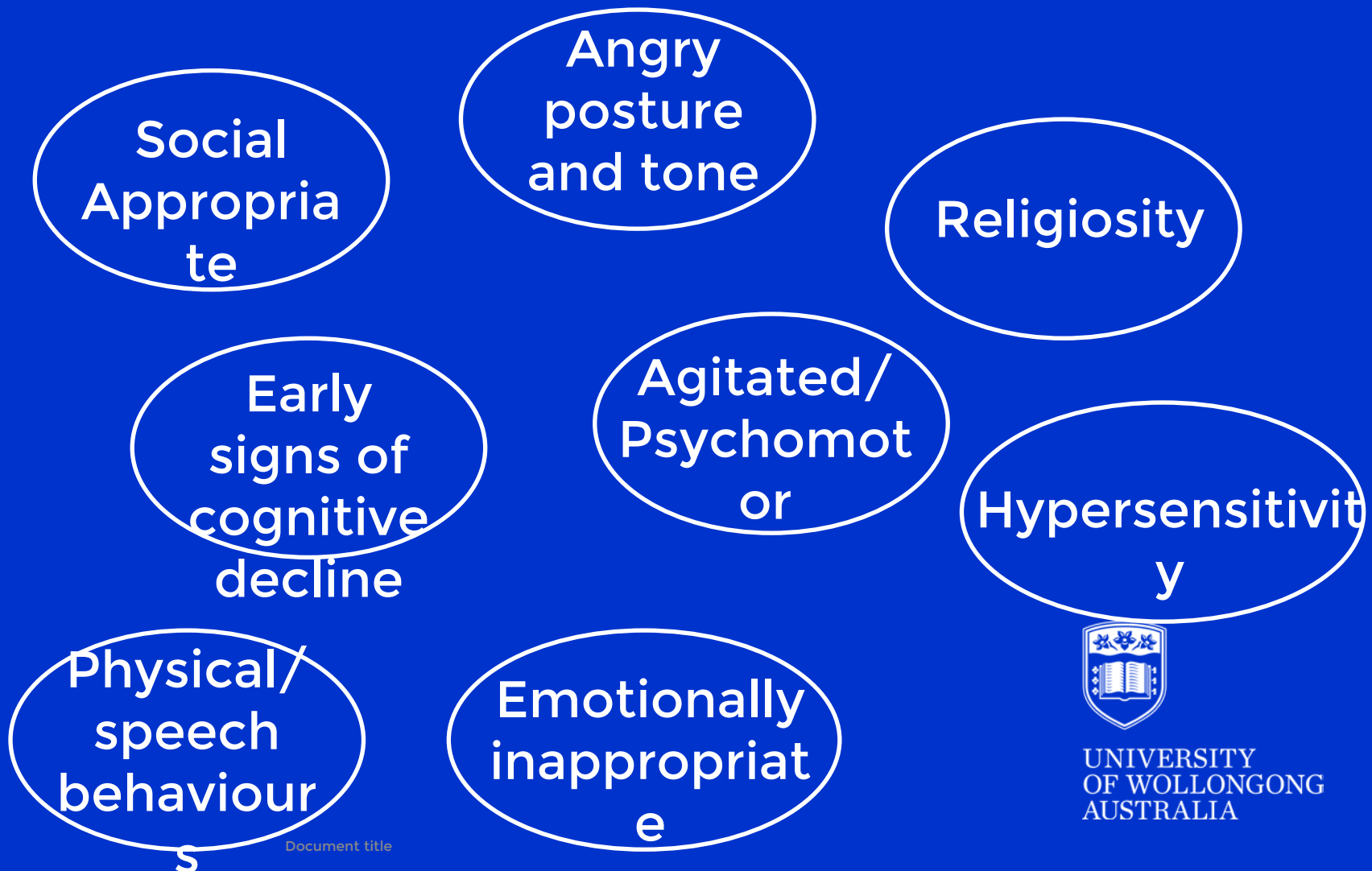
- ❖ Similar findings for academics and practitioners (mean number of categories of 11 for both)

- ❖ Different findings between the most represented disciplines of nursing and psychology/ counselling (mean number of categories 9 and 16 respectively)

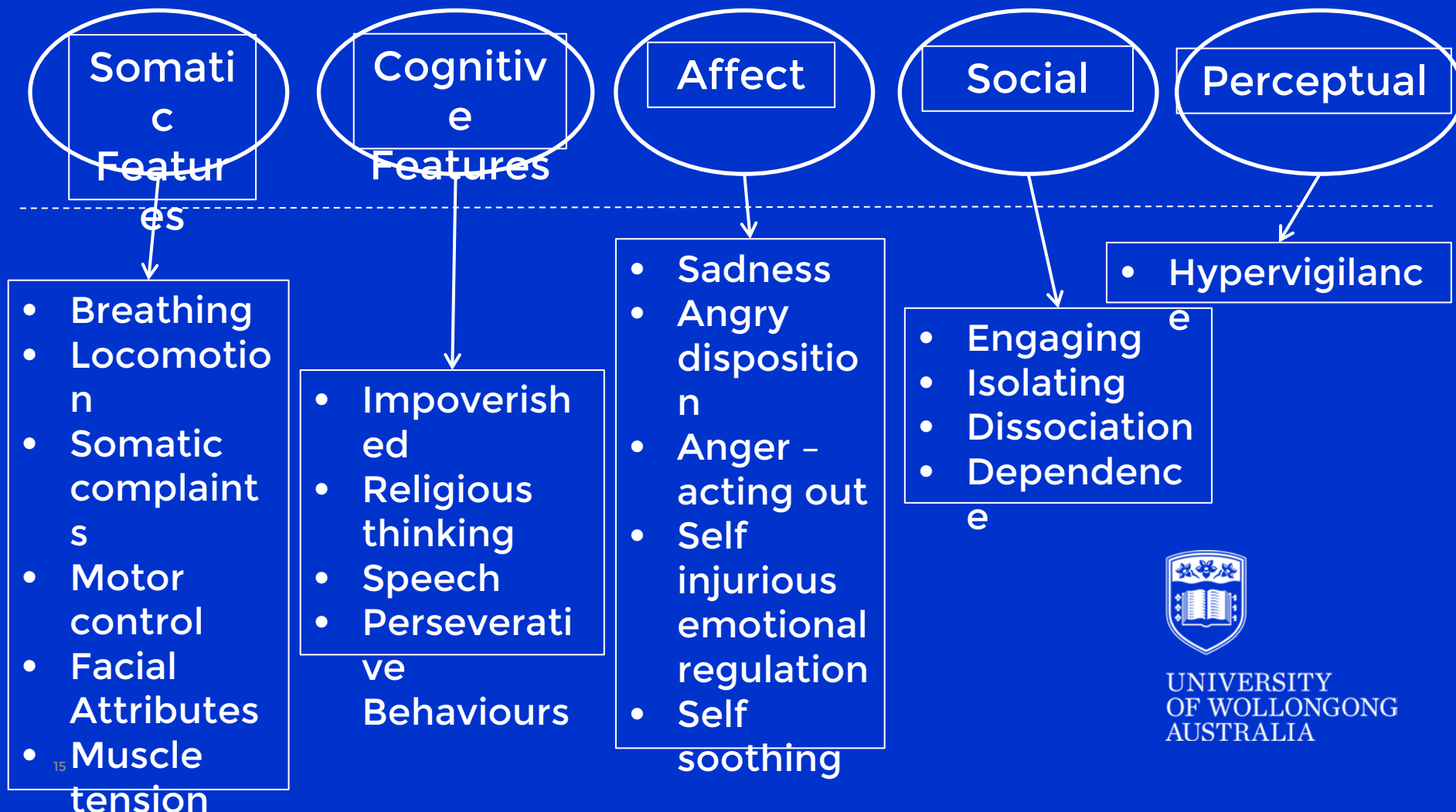


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Q Sort: Example of simple model



Q Sort: Example of complex model



What's next for the FADe Tool?

- ❖ Complete Q Sort activity
- ❖ Delphi survey to develop Draft 5 to ensure items included have the highest level of agreement among participants about their representation of fear and anxiety for individuals living with a dementia
- ❖ Reliability and validity testing, including factor analysis to develop final version of FADe tool
- ❖ 2017: Launch FADe Tool
- ❖ Future studies
 - Developing digital version of tool for clinical partners
 - Filmed vignettes demonstrating the use of the FADe Tool in practice (UOW)
 - Intervention study using the fear and anxiety tool in dementia as an outcome measure



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Clinical implications

- ❖ FADe tool will be used by practitioners to recognise and assess fear and anxiety experienced by individuals living with a dementia
- ❖ FADe tool will be promoted as a tool which can be used to plan the ways in which practitioners work with individuals living with a dementia
- ❖ FADe tool will be used to structure education activities with practitioners to create environments (physical and caring relationships) which are less fearful for individuals living with a dementia
- ❖ Using the FADe tool has the potential to begin conversations among practitioners



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Questions and comments

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